

Symposium Commentaries

Office of Management and Budget Racial Categories and Implications for American Indians and Alaska Natives

ABSTRACT

This commentary provides a brief overview of American Indian and Alaskan populations in the United States and selected data issues. The focus of this commentary is an excerpt of recommendations related to Office of Management and Budget Directive 15 (racial categories) and American Indians and Alaska Natives.

Of paramount concern is not only that all federal, state, and local agencies collect data on American Indians and Alaska Natives, but also that reports, findings, and peer-reviewed publications include data on American Indians and Alaska Natives. It is of no use to recruit American Indians and Alaska Natives into studies and projects if their race/ethnicity-specific data are not disseminated.

Collapsing racial/ethnic categories, such as Asians, Native Hawaiians and Pacific Islanders, and American Indians and Alaska Natives, into a single racial category of "other" is of no benefit to public health policymakers, researchers, and tribal planners. Likewise, tribal affiliation should be collected whenever it is feasible to do so. Insufficient inclusion and inaccurate identification of American Indians and Alaska Natives in national surveys has also resulted in a dearth of baseline data in significant reports such as *Healthy People 2010*. (*Am J Public Health*. 2000;90:1720–1723)

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American Indians (which includes all tribes and clans of indigenous native peoples of the continental United States) and Alaska Natives (which includes all tribes and clans of indigenous natives of Alaska) are the smallest racial/ethnic groups in the United States. Approximately 1.9 million people (0.8% of the US population) were self-identified as American Indians and Alaska Natives (also known as Native Americans) on the 1990 US census.¹ American Indians and Alaska Natives comprise more than 554 federally recognized and diverse groups of indigenous populations with distinct cultural backgrounds. Contrary to popular perception, the 1990 census indicated that only 19.8% of all American Indians live on federal reservations, and more than 60% of the population reside in urban areas.

In 1989, twice as many American Indians and Alaska Natives (30.9%) as the total US population (13.1%) lived at or below the poverty level. The percentage of White people living at or below the poverty level in 1989 was 9.8%. The median family income in 1989 for indigenous peoples was \$20025 and for White people was \$31435.¹ Much as with other Native American groups, the socioeconomic conditions of Alaska Natives are poor. In 1980, approximately one fourth of Alaska Native families lived below the poverty level.

Any public health professional is well aware of the importance of accurate data. Well-documented limitations in public surveillance and data systems have been published elsewhere.^{2–10} The lack of appropriate and adequate data in American Indian and Alaska Native communities has multiple implications (see Table 1). For example, in 1998, the National Cancer Institute, American Cancer Society, and Centers for Disease Control and Prevention released a report stating that cancer prevention, detection, control, and treatment have improved significantly, leading to the first overall decline in the cancer mortality rate in the United States.¹¹ Closer examination of the

data revealed that minorities and medically underserved populations were less likely to share this cancer experience benefit.¹²

In this commentary, we focus on recommendations related to the Standards for the Classification of Federal Data on Race and Ethnicity (also known as Office of Management and Budget [OMB] Directive 15) and American Indians and Alaska Natives.

Selected Recommendations Related to OMB Directive 15 and American Indians and Alaska Natives

The OMB held town meetings during the mid-1990s to solicit public comment on the use of racial/ethnic categories, then referred to as OMB Directive 15.¹³ "American Indian and Alaska Native" has been a separate racial category, according to the OMB, since 1977. The 1997 Refinement of OMB Directive 15 retained "American Indian and Alaska Native" as a distinct racial/ethnic category.

Recommendation 1: All federally funded research and service projects should be mandated to implement OMB Directive 15 racial categories when providing study findings. Although such racial/ethnic data are frequently collected, when study findings are released, the racial/ethnic categories are usually limited to non-Hispanic/Latino Whites (Caucasian), Blacks (African American), Hispanic/Latinos,

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TABLE 1—Implications of “Accurate” and “Inaccurate” American Indian and Alaska Native Health Data

Potential Beneficial Uses of Accurate Data	Potential Hazards of Inaccurate Data
<ol style="list-style-type: none"> 1. Help tribal nations, health boards, and urban Indian clinics identify health priorities. 2. Help funding agencies recognize unmet needs within selected communities. 3. Justify the need for unique programs within tribes, counties, states, regions, and territories (data from 1 region of the country cannot be generalized to another region or tribe, so use of data from a southwestern region misrepresents the seriousness of selected problems among Northern Plains tribes). 4. Document behavioral practices that are related to health and disease. 5. Clarify the disparity and variation in disease rates among population groups. 6. Clarify the effect selected behaviors have on disease or health in selected populations or regions of the country. 7. Document unique disease patterns among small communities (who remain underserved communities). 8. Obtain sufficient resources to address selected health problems. 9. Set research priorities at federal (e.g., Department of Health and Human Services, National Institutes of Health, Centers for Disease Control and Prevention, Indian Health Service) and state agencies <i>to serve the needs of American Indian and Alaska Native communities</i>. 10. Allow tribal health data to be compared with data for other medically unserved or underserved populations and nations. 11. Document health trends over time. 	<ol style="list-style-type: none"> 1A. Limited tribal fiscal resources are allocated for problems that may be of less concern to the local community. 1B. Insufficient data are interpreted as <i>there not being a problem</i> rather than as a data error or lack of inclusion in data collection (e.g., low participation in Behavioral Risk Factor Surveillance System caused by lack of telephones). 2. Funding agencies do not support selected programs because the health condition is “unrecognized” as a problem by the data. 3. Funding agencies erroneously assume that data from 1 part of the country are generalizable to another tribal community. Thus, if smoking is not a problem in the Southwest, the agency may believe it is not a problem among Northern Plains tribes. 4. Lack of data is interpreted to mean that <i>there is no problem behavior</i> (e.g., habitual tobacco use). 5. Unique patterns of disease for a specific tribal community are not identified as problems or addressed. 6. Lack of local behavioral data frequently results in inaccurate conclusions (e.g., elevated suicide rate among northwestern tribes was not associated with the events, such as caring for a dying family member and insufficient grief support). 7. Unusual patterns continue to go unnoticed by local tribal programs, and subsequently more community members can be affected (e.g., HIV and sexual activity with multiple partners). 8. Infrastructures (including staff, facilities, resources on and off the tribal community reservation) are not available to support the growing health problem. 9. Federal documents tend to use New Mexico or Arizona data when setting research priorities. Thus, elevated problems for other tribal communities are not acknowledged in federal priorities (e.g., Native American breast cancer). 10. Insufficient and inaccurate health data prohibit comparisons among (1) tribes, (2) underserved populations (e.g., Native Hawaiians and American Indians), and (3) racial/ethnic groups (e.g., Native Americans and Whites). 11. Inability to determine if a health problem is “new” or simply previously undocumented.

and “others.” Collapsing the diverse smaller population groups into an “other” category excludes all racially specific information and cultural relevance. “Other” data are of no use when one is attempting to develop, assess, and monitor public health programs and services. “Other” data have the same effectiveness as having “no” data.

Recommendation 2: Studies that have small numbers of selected racial groups should still publish results as specified within OMB Directive 15. Public health professionals are frequently asked to assist with the recruitment and retention of medically underserved populations, such as American Indians and Alaska Natives, in service and research projects. In spite of recruitment efforts, minorities and medically underserved populations may have few participants. Regardless of the small numbers of participants, data need to be provided for all racial/ethnic categories. These data should include the raw number, percentage, and confidence interval whenever appropriate. In addition, a footnote should be linked with the confidence interval to explain that the larger

the confidence interval, the more likely the data are to be random and therefore inaccurate. The opinion among many of those who work with small populations within the public health field is that limited data are better than “no” data.

Many public health professionals implemented innovative recruitment strategies for studies such as the Women’s Health Initiative. If OMB Directive 15 racial categories are not included for summary reports, how likely are American Indians and Alaska Natives to participate in subsequent studies? A common and unfortunately valid complaint among American Indians and Alaska Natives is that they take part in studies but never see any results relevant to their group. At the same time, many tribal nations are creating increasingly stringent research protocols that mandate sharing of research findings with study participants.

Recommendation 3: Special efforts should be made to ensure the inclusion of medically underserved populations within large-scale national and state surveys and surveillance systems. American Indians and Alaska Natives

are rarely included in sufficient numbers on national health surveys such as the National Health Interview Survey, National Health and Nutrition Examination Survey I and II, Behavioral Risk Factor Surveillance System, National Medical Expenditures Survey, and National Survey of Family Growth.

*Healthy People 2010 Objectives for the Nation*¹⁴ is produced by the federal government and includes hundreds of objectives to assist with the setting of priorities for health programs. Of the 128 objectives that are population-specific to American Indians and Alaska Natives, more than half (n=78, 61%) have no baseline data. Primary data sources for *Healthy People 2010* are the National Health Interview Survey, National Health and Nutrition Examination Survey I and II, Behavioral Risk Factor Surveillance System, National Medical Expenditures Survey, and National Survey of Family Growth. As a result, some of the national objectives result in little to no baseline data for American Indians. For example, the nutrition subject has 13 population-specific objectives, for which only 2 have any baseline

data. In general, the objectives for which data exist (e.g., cancer) greatly underreport health problems because the federal agencies lack quality data for American Indians or refuse to use alternative sources of federal data (e.g., Indian Health Service resources).

When American Indians and Alaska Natives are included in surveys, studies, demonstration projects, and peer-reviewed publications, the findings should also include data from those populations. Publication guidelines may be modified to reflect a policy that emphasizes the dissemination of racially specific study findings.

Recommendation 4: Racial misclassification and similar errors need policies/process/protocols that allow organizations and agencies to share corrections and that enable those corrections to be incorporated into national surveillance and database systems. Racial misclassification is the most common error affecting American Indian and Alaska Native data. The major explanations for racial misclassification are (1) the use of Spanish surnames to determine a person's race and (2) the use of personal observation by data collectors in completing the race item on death certificates and other health records. Additional misclassification occurs for reasons including, but not limited to, the following: (3) American Indian-Alaska Native is not a response category in medical records (e.g., hospital, health clinic), (4) definitions of American Indians are imprecise and inconsistent, and (5) self-identification changes. Self-identification can change when a formerly "unrecognized" tribe becomes federally recognized by Congress, when tribal enrollment ordinances change (e.g., minimum blood quantum of 25% vs proof of Indian ancestry), or when tribal enrollment ordinances change regarding paternal vs maternal lineage.^{10,15,16}

When racial misclassification errors are identified, the tribal, state, and surveillance systems need to implement corrections and share them with federal agencies. As a result of stellar efforts to match tribal enrollment records with state databases, local tribes have improved the accuracy of their surveillance systems. However, when errors are noted on American Indian records (e.g., a birth certificate listing an American Indian as "White"), the tribes are frequently prohibited from sharing the corrected information with the state programs for fear of violating confidentiality (e.g., the American Indian individual fears racism in the workplace if others know of his or her racial/ethnic background). In other cases, the Tribal Health Board has allowed tribal programs to share such data with the state, but the federal government has refused to accept the data (and subsequently refused to correct the racial misclassification in the federal database). Collab-

oration is needed among tribal nations, rural and urban Indian health boards, state departments, and federal government agencies to determine an ethical and practical way to reduce racial misclassification in existing databases and study results. Suggestions for how to reduce misclassification at the time of data collection have been published elsewhere and include providing race-specific training for clinic, hospital, and institutional staff on how to ask about race/ethnicity.^{2-4,6-10,15}

Recommendation 5: When feasible, American Indian and Alaska Native racial/ethnic data collection should allow for specification of tribal affiliation. OMB Directive 15 specifies the American Indian and Alaska Native race identification. When feasible, an additional option on tribal affiliation should be included at the time of data collection. Just as American Indian and Alaska Native data provide guidance to public health policymakers, researchers, community health educators, and so on, tribally specific data greatly assist in the development of local prevention and intervention programs and projects. For example, the California Health Interview Survey will collect OMB Directive 15 racial/ethnic category information as well as allow data collectors to ask about tribal affiliation.

Recommendation 6: Partnerships for the collection of geographically diverse tribal data need to be created, implemented, and supported between tribal nations and urban and national Indian organizations on the one hand and federal agencies, state governments, and national organizations, such as the American Cancer Society, on the other. Tribal communities and organizations (local, regional, and national) need to be included as partners in all data collection efforts and data storage. Selected efforts, such as the Cancer Surveillance System within the Northwest Tribal Cancer Control Project supported through the Centers for Disease Control and Prevention, have produced cancer incidence and mortality data that were previously and erroneously regarded by Native Americans and non-Native Americans alike as suggesting that cancer is a rare health problem among Native Americans. Examples of national Native American organizations with whom federal agencies, states, and tribes could collaborate are the Alaska Native Health Board, Alaska Native Science Commission, National Indian Center on Aging, National Indian Health Board, and Indian Health Service Epidemiology Centers.

Recommendation 7: For small racial communities, carefully consider when it is best to "mark all that apply" as compared with marking only 1 race for multiracial individuals. The 2000 census and other data collection instruments are conforming to OMB Directive 15 by allowing individuals free choice

in identifying their racial and ethnic categories. For example, multiracial individuals are no longer limited to marking 1 racial group but can acknowledge their varied racial backgrounds by marking all racial categories that apply to themselves. The OMB town meetings provided sufficient public input and rationalization for this inclusion.

However, for small populations, such as American Indians and Alaska Natives, multiple informal efforts were initiated by community members to encourage marking only American Indians and Alaska Natives, even if the individual were multiracial. Community members recommended that multiracial American Indians and Alaska Natives check "no" on the Hispanic/Latino origin question, check only 1 race ("American Indians and Alaska Natives"), and write in the name of their tribe. As a result, sufficient American Indian and Alaska Native data are more likely to be available in the census and other publications and reports of study results. This effort was driven by the concern that multiracial/ethnic persons with American Indian and Alaska Native heritage would not be tabulated as American Indians and Alaska Natives.

Summary

The more than 554 federally recognized tribes, the numerous state-recognized tribes, and the numerous self-identified American Indians and Alaska Natives do not now belong, nor have they ever belonged, to 1 pan-Indian group. Although indigenous peoples have similarities, many cultural, behavioral, and social differences must be taken into account. The issue for public health interventions is that data are insufficient to describe the health status of a tribe or an urban Indian community, the locus of interventions. Sufficient data related to health status are necessary to make informed policy, planning, and resource allocation decisions for the health improvement of the population. □

Contributors

L. Burhansstipanov and D.E. Satter contributed equally to the writing and editing of the commentary.

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